

October 28, 2013

Ms. Krysta Heaney Policy Analyst JRTC 100 W. Randolph, Suite 4-750 Chicago, IL 60601

Dear Ms. Heaney:

On behalf of the 11,000 member physicians of the Illinois State Medical Society ("ISMS"), I am writing to thank you for allowing our participation in the ILHIE Patient Choice and Meaningful Disclosure Work Group ("work group"). Throughout the process, ISMS has voiced concern over numerous aspects of the documents developed by the ILHIE Authority and work group. These issues remain important to physicians and we ask that you strongly consider our recommendations, enumerated below. All comments are specific to the draft versions from 10/24/13.

EHR Connect Non-Participation Form (Opt-Out)

- Patient consent: as written, the form allows for a 12 year old to consent to participating in EHR Connect, even those 12 year olds who do not otherwise have the ability to consent by virtue of special circumstance, such as pregnancy or emancipation. This purports to create a right for 12 year olds that is not based in the law nor is supported by other legal authority. During work group discussions, no one was able to provide a legal basis for this. Rather, a dual consent requiring signature of both a parent/legal guardian and those minors between the ages of 12 and 18, who would not otherwise be able to consent, solves this problem. The minors are part of the decision-making, and if they refuse to consent, they will not be part of EHR Connect. This also provides protection for physicians, who have the burden of discussing the EHR Connect service with patients and will be intimately involved with the consent process.
 - o Recommendation: change to require dual consent
- Notary: during the meeting on 10/16, ILHIE staff indicated they would remove notary requirement and replace with a witness requirement. A witness, not a notary, is the requirement for both the Power of Attorney for Health Care (755 ILCS 45/4-10) and the Power of Attorney for Property (755 ILCS 45/3-3). Furthermore, a notary requirement is anti-consumer and will delay patients in submitting their Participation and Non-Participation Forms.
 - Recommendation: remove notary requirement as agreed on 10/16
- <u>Separate section for witness</u>: ISMS recommends the inclusion of a dashed line between Option 1 and Option 2 to denote the separate witness requirement that must be completed.
 - o Recommendation: include a dashed line between Option 1 and Option 2

ILHIE's HER Connect Opt-In Form

- Specially protected health information: "certain alcohol and substance abuse treatment information" needs to be defined. As written, this is incredibly vague. Patients and health care providers and professionals deserve to know what ILHIE thinks can and cannot be shared.
 - o Recommendation: define "certain alcohol and substance abuse treatment information"
- We also repeat the same comments as above on the EHR Connect Non-Participation Form (Opt-Out)

Notice to Patients Regarding the Illinois Health Information Exchange's EHR Connect

- Some alcohol or drug abuse health care providers: as written, this is vague. Patients deserve to know which providers are affected. Simply including a link to a website, as brought up during the 10/16 meeting, is not sufficient and does nothing for patients that receive a paper notice.
 - o Recommendation: define "some alcohol or drug abuse health care providers"
- Patients under 12 years old: the notice allows for a 12 year old to consent to participating in EHR Connect, even those 12 year olds who do not otherwise have the ability to consent by virtue of special circumstance, such as pregnancy or emancipation. This purports to create a right for 12 year olds that is not based in the law nor is supported by other legal authority. During work group discussions, no one was able to provide a legal basis for this. Rather, a dual consent requiring signature of both a parent/legal guardian and those minors between the ages of 12 and 18, who would not otherwise be able to consent, solves this problem. The minors are part of the decision-making, and if they refuse to consent, they will not be part of EHR Connect. This also provides protection for physicians, who have the burden of discussing the EHR Connect service with patients and will be intimately involved with the consent process.
 - o Recommendation: change to require dual consent

ILHIE Policies and Procedures

- "Specially Protected Health Information," Section I, p. 2: the definition states this includes "certain alcohol and substance abuse information." Again, this is vague and both patients and health care professionals and providers deserve to know what ILHIE thinks can and cannot be shared. Additionally, the last part of the sentence states that these types of information require "patient consent," but in actuality, specific written patient consent is required.
 - Recommendation: define what is "certain alcohol and substance abuse information"
 - o Recommendation: change "patient consent" to "specific written patient consent"
- Procedures, Section III, Part A, item 12: the policy states that a 12 year old may consent to participating in EHR Connect, even those 12 year olds who do not otherwise have the ability to consent by virtue of special circumstance, such as pregnancy or emancipation. This purports to create a right for 12 year olds that is not based in the law nor is supported by other legal authority. During work group discussions, no one was able to provide a legal basis for this. Rather, a dual consent requiring signature of both a parent/legal guardian and those minors between the ages of 12 and 18, who would not otherwise be able to consent, solves this problem. The minors are part of the decision-making, and if they refuse to consent, they will

not be part of EHR Connect. This also provides protection for physicians, who have the burden of discussing the EHR Connect service with patients and will be intimately involved with the consent process.

- o Recommendation: change to require dual consent
- <u>Procedures, Section III, Part A, item 13</u>: the policy states that upon reaching age 12, a minor patient has the right to exercise their consent and revise the previous consent decision of their parent or legal guardian. There is no basis in the law for this, similar to item 12 above.
 - o Recommendation: remove Section III, Part A, item 13
- <u>Procedures, Section III, Part A, item 14</u>: this item incorrectly states the policy and should be clarified. Patients with specially-protected health information should not have their personal demographic information shared upon enrollment of the EHR Connect User.
 - O Recommendation: change item 14 to read "Upon enrollment in EHR Connect, an EHR Connect User will electronically supply the ILHIE with personal demographic information about all of the user's patients except those with specially-protected health information so that other participating EHR Connect Users may access the EHR Connect User's patients' health information, if available, for Authorized Purposes."
- <u>Procedures, Section III, Part A, item 15</u>: the communication of elections requirement is confusing and needs to be clarified. As written, EHR Connect Users are subject to three different rules for submitting elections.
 - o Recommendation: clarify the time period for election submission.
- <u>Procedures, Section III, Part A, item 17</u>: this section provides protections for patients who optout, but not those who participate.
 - o Recommendation: revise item 17 to read, "The EHR Connect User will not deny care to any patient because he or she elects to participate in or opt out of EHR Connect.
- <u>Procedures, Section III, Part C, item 6</u>: this item incorrectly states the policy and should be clarified. Patients with specially-protected health information should not have their personal demographic information shared upon enrollment of the EHR Connect User.
 - Recommendation: change the first sentence in item 6 to read, "Upon enrollment in EHR Connect, an EHR Connect User will electronically supply the ILHIE with personal demographic information about all of the EHR Connect User's patients except those with specially-protected health information."
- <u>Procedures, Section III, Part C, item 8</u>: this item misstates the policy. It states that for patients that have opted out, EHR Connect will not disclose any information on the patient except as permitted by law. Why does EHR Connect have any information at all on this patient?
 - Recommendation: revise item 8 to read "For a patient that has opted out of EHR
 Connect, the ILHIE Authority will not disclose health information for any purpose
 except as permitted by law such as public health reporting. Instead If opted-out, a

message will be sent to the querying EHR Connect User to the effect there is 'no information available.'"

Thank you very much for this opportunity to comment. If you have any questions please do not hesitate to contact either myself (<u>kane@isms.org</u>), Sherri DeVito (<u>sherridevito@isms.org</u>) or Amanda Attaway (<u>amandaattaway@isms.org</u>).

Sincerely,

Robert John Kane Legal Counsel